



**National Voices**

People shaping health  
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# National Voices

## **NATIONAL VOICES' RESPONSE TO THE CONSULTATION: Strengthening the NHS Constitution January 2013**

### **OVERVIEW**

- On the whole, National Voices welcomes the proposed amendments to the content of the NHS Constitution.
- However, there are a number of ways that the amendments could be strengthening further, to provide greater clarity in relation to key agendas upon which the Government has already expressed its support at policy level.
- We are calling for:
  - a right to care planning for those who will need to use services over time
  - recognition of the role of advice and advocacy in enabling patient involvement
  - every NHS Trust to have systematic, frequent and comprehensive patient experience measurement
  - a statutory duty of candour
  - the wording on integration to reflect the [Narrative](#) being developed with the NHS Commissioning Board and the Local Government Association
  - clear articulation of the need for integrated working with other services, such as social care and housing
  - one simple and clear route of complaint and appeal for patients
  - common standards in care records
  - training to support new staff in delivering duties on patient involvement, health inequalities and public health
  - a commitment to move parity of esteem beyond the rhetoric by referencing mental health pathways within the document (e.g. equal applicability of the 18 week waiting time pledge to both physical and mental health)
  - all letters to a patient to be addressed to that patient, and copied to the GP or other consultants as necessary

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## 1. ABOUT NATIONAL VOICES

National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 150 members with 130 charity members and 20 professional and associate members. Our broad membership, rooted in people's experience, represents millions of individuals, and covers a diverse range of health conditions and communities.

Jeremy Taylor, National Voices' Chief Executive, has been working closely with the NHS Future Forum working group to feed in our members' views in relation to strengthening the NHS Constitution over the last few months. This response presents some key recommendations drawn from these ongoing discussions.

## 2. OVERVIEW

On the whole, National Voices is supportive of the ten areas in which the consultation proposals amendments. However, there are a number of ways in which the content of the document could be strengthening further, to provide greater clarity in relation to key agendas upon which the Government has already expressed its support at policy level. More detail on these recommendations is provided below.

There was general consensus that although updating the content of the document is an important exercise, the greatest value will be derived from raising awareness amongst patients and staff and ensuring that it has 'teeth'. We have included some draft ideas about how this can be done in practice under Section 4 below but we will be looking to submit a more detailed response to the second consultation in due course.

## 3. NATIONAL VOICES' RESPONSE TO THE CONSULTATION CONTENT

### 3.1 Patient involvement

National Voices welcomes these changes, many of which reflect the suggestions made in our submission to the Future Forum. There is increasing understanding that involving each patient in their own care and treatment is not only a right in itself but an important contribution to developing a high quality and sustainable health service.

The proposed amendments in relation to end of life care and right to involve family members and carers are particularly positive. The latter echoes the draft wording of the Care and Support Bill and recognises that decisions in healthcare rarely affect a single individual, but also impact upon their wider social networks.

However, there are also a number of areas in which the proposals can be further strengthened.

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Firstly, it remains important that the amendments fully recognise the **fundamental importance of building people's knowledge, skills and confidence to enable them to become effectively involved** in practice. We very much welcome the recent inclusion of this point under the long term conditions section of the [Mandate to the NHS Commissioning Board](#).

The current amendments to incorporate rights in relation to information on test and treatment options and potential risks and benefits and 'support to use it' are positive, but the nature of this support should be more clearly defined. The document currently makes **no reference to access to advice and advocacy services** which play an important role in enabling people to make the right decisions for them and helping them develop a better understanding of their condition and, where appropriate, self manage.

Secondly, it is positive that the **critical importance of involving patients in care planning discussions** is acknowledged in the proposed amendments. However, National Voices members argue that this **should be included as a patient right rather than a pledge**.

There has been significant recognition across the policy spectrum of the central role of care planning in improving quality of care and supporting better patient outcomes.

In social care, the wording of the draft Care and Support Bill sets out a clear starting point for genuine care planning processes in statute, and we are working with the Care and Support Alliance to strengthen and develop this provision. A key amendment proposed in the course of our work here is to acknowledge health needs as a part of the care planning process in social care to encourage the involvement of patients in discussions about their care in more a holistic way.

Most recently, the Mandate to the NHS Commissioning Board included a commitment for 'everyone with long-term conditions, including people with mental health problems, [to] be offered a personalised care plan that reflects their preferences and agreed decisions'. This builds on a number of existing commitments, NICE standards and individual rights for certain patient groups, which have been incorporated in statute over the years.

National Voices members are now eager to see these commitments to **care planning** come together **as a clearly articulated right where it is expected that you will need to use services over time**.

This will send a clear message to professionals about the importance of patient involvement, promote investment in the skills and knowledge required to deliver it effectively and clarify patient entitlements.

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National Voices is looking to work with its members to develop a narrative on care planning and we would be happy to meet with departmental colleagues to discuss this proposed amendment in more detail.

## 3.2 Feedback and patient experience

National Voices welcomes this clarification and the change in culture that it seeks to promote but we are aware that there is still a long way to go.

The 2011 national inpatients survey found that 87 per cent of respondents said they were not offered the opportunity to give their views on the quality of care but patients and family members are often the first to notice when care standards are not as high as they should be.

Providers of care must gather good evidence about the experience and views of patients and families, making it very easy for people to offer feedback at the point of care, as well as later. This is currently a regulatory outcome monitored by the Care Quality Commission but we are convinced that there is more to be done here.

We want **every NHS organisation to establish patient experience collection that is systematic, frequent and comprehensive, with the results reported to all levels of management.** The purpose of these systems should be for continual quality improvement, but they should also have the effect of ensuring there is no hiding place for pockets of poor care, such as a bad ward. NHS Northumbria Foundation Trust is an exemplar here.

Boards of organisations must treat it as a priority to collect and analyse suitable information and act upon it – and they should be held to account for how well they do this. It should be impossible to ignore feedback, which should be embraced as a tool to improve care and, in some cases, to give warning lights.

No single source of information is likely to be sufficient to give care providers a full and rounded picture of how well they are doing. The “Friends and Families Test” favoured by the Government is a high level and superficial measure and it would be unwise for the NHS to place undue reliance on it.

### **Case study example: Developing an ‘M-PROM’**

Arthritis Research UK is working with the musculoskeletal community and expert academic groups to develop a standard ‘M-PROM’ (Patient Reported Outcome Measure) for musculoskeletal health problems. People with these conditions may require support from primary and specialist care, and professions including physiotherapy, GPs, rheumatologists and orthopaedics. Patient reported measures are an ideal way to monitor musculoskeletal health status which cannot be simply captured using a biological measure (in the way that blood sugar, or blood pressure can in other conditions).

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The M-PROM is intended to be used by people with a wide range of musculoskeletal conditions to report on their health, regardless of the setting in which they are receiving care. It has the potential to support improvement in clinical practice, and self-management, by enabling more effective monitoring of health status.

### 3.3 Duty of candour

Although the amendments are a step in the right direction, National Voices is concerned that the Government has not committed to creating a statutory duty of candour. Even if the wording of the existing pledge is strengthened, this does not go far enough to ensure that patients have immediate access to information about issues relating to their own care and proper recognition of where things have gone wrong.

Only a **statutory duty** would:

- cover *all* providers of NHS services including dentists and, in due course, GPs
- ensure that all organisations need to demonstrate that they have “taken all reasonable steps” to ensure openness with patients (having policies and procedures in place, including training and support of staff in ‘being open’)
- redress the current imbalance in requirements - there is a statutory requirement for providers to report patient safety incidents to the CQC but *no statutory* requirement to report them to the patients affected
- bring England up to speed with Wales, France, Sweden and various other countries, which have already built this in to legislation.

A joint briefing with AVMA and NALM on this issue can be found [here](#).

Finally, the wording of the Constitution doesn’t make it clear that, as things stand, the NHS is only committing to ensure openness from organisations with an NHS contract. This does not include other important service providers, such as GPs and dentists.

### 3.4 Making every contact count

In theory, National Voices welcomes this proposal as a way of maximising the impact of the time spent with patients and service users. However, it will be important to consider both how patients will be involved in this process and how staff can be supported to deliver this responsibility effectively.

Patients are more likely to adapt their health behaviours if they are involved in setting goals and discussing the best ways to reach them. Where staff do not have sufficient training, brief interventions may come across as superficial ‘lectures’ which are unlikely to impact on better health outcomes. In some cases, it may be more effective for patients to be **referred to appropriate providers of peer support**,

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**health literacy and self-management advice, including voluntary and community sector providers and/or non-medical health staff**, who can provide them with more detailed, personalised information and support over time. This may involve ensuring the widespread availability of lifestyle intervention programmes to support people in changing their behaviour.

## 3.5 Integrated care

National Voices welcomes this proposal to strengthen the language on integrated care in the Constitution. It will be important that any changes in wording are also supported by practical examples and work streams which support commissioners and providers in understanding what coordination really means from those receiving services and provides them with practical approaches which they can adapt and incorporate in their day to day work.

National Voices is currently working with the NHS Commissioning Board and the Local Government Association to create a [Narrative](#) which defines integration as 'person-centred coordinated care', and elaborates this through a set of statements developed by service users themselves.

This will be a key piece of the national system 'framework' for integrated care and it will be important to acknowledge this work when finalising the amended wording and clarifying the responsibilities in the revised handbook.

It will also be important to think about how the **NHS promotes integrated working with other services, such as social care and housing**, and whether this could be specified more directly in relation to Principle 5. With growing focus on care coordination, there would be great merit in considering how the content of the draft Care and Support Bill could be borne in mind in the revised Constitution, to help people to better understand how the 'NHS offer' and the minimum 'social care offer' are supposed to come together.

National Voices is working with the [Care and Support Alliance](#) to consider how these two pieces of legislations can be effectively connected and would be happy to discuss with officials how these connections could be reflected in the NHS Constitution.

## 3.6 Complaints

National Voices welcomes the Government's intentions to update the NHS Constitution in line with the current legislation. However, there are two ways in which this point can be further strengthened.

Firstly, the handbook should be revised to define clearly how people can seek redress against **each specific right**. This should clarify one simple first route of complaint and appeal to help patients fully understand the process.



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In addition to making the process easier to navigate, we are also eager to see how **meaningful and comparable information on complaints can be used to drive improvements, strengthen the quality of service and improve patient experience.**

Linked to the point on feedback above, we are confident that better access to data on how services are performing would:

- enable providers to identify trends/patterns of risk, take appropriate action and demonstrate how they have learned from their mistakes;
- commissioners to hold providers to account for the above processes;
- regulators to identify underperformers and take appropriate action;
- enable local Healthwatch to monitor areas of local concern;
- provide Healthwatch with meaningful data to inform its work and priorities and
- enable patients and services to make more informed choices and have greater confidence in the complaints handling process.

Finally, the **current wording on compensation** (*'You have the right to compensation where you have been harmed by negligent treatment'*) **is misleading**. Currently, no one has a *right* to compensation; just a right to make a claim for it (if the person is aware of what happened and has the time and means to progress a claim). The preceding paragraph about judicial review (you have a *right to claim*) is more accurate.

### 3.7 Patient data

National Voices largely welcomes this proposal. Information sharing is an important prerequisite for people being involved in decisions about their own care and treatment and the care of family members. As outlined in a recent [British Heart Foundation report](#), enabling appropriate access to medical records can also play a significant role in medical research and assist the recruitment of patients for clinical trials.

We welcome the inclusion of the existing legal right to be informed about how your information is used but would encourage clear definition of the wording 'those involved in your care' to ensure that people are appropriately safeguarded and patient confidentiality is respected. The definition should include carers and family members, with the consent of the patient.

However, we would urge the Department to remember that it is not only a question of having access to your data but **also being able to amend it**, where appropriate. This may have significant patient safety implications in relation, for example, to recording allergies or how patients responded to certain types of treatment.

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Finally, we are keen to see some progress made on the issue of **common standards in care records**. In December 2011, we worked with a broad range of colleagues to draw up the report '[Developing standards for health and social care records](#)' in which we support the establishment of a Professional Record Standards Development Body (PRSDB) to have oversight over the way in which records are structured to ensure their interoperability in relation to IT and content.

### 3.8 Staff rights, responsibilities and commitments

National Voices agrees that it is important that staff feel both supported to conduct their duties and empowered to raise any concerns or suggest ways to improve service delivery.

As noted above, **training on their new duties on patient involvement, health inequalities and public health will be critical in ensuring that staff feel confident to deliver them**, and recognise their role in improving patient outcomes. It will be important that these are recognised as a strengthening of their role and not just additional duties in an ever-growing job description.

Linking to the point on feedback, staff need to feel that they operate in a sufficiently open working environment in which they are listened to, and their concerns or suggestions are actioned. Given their proximity to the patient and their experiences of services, front line staff are well placed to understand when things are or aren't working and make suggestions about how services can be delivered more effectively. The amended wording will lay the foundations, but there will also need to be concrete mechanisms to promote this change in culture in practice.

### 3.9 Parity of esteem between mental and physical health

National Voices welcomes this upfront commitment to parity of esteem. Evidence indicates strong links between mental and physical health amongst a wide range of conditions (e.g. arthritis and depression) and this equal focus will be a critical step towards viewing people in a more holistic way. However, we call for sufficient focus on practical implementation to ensure that the notion is more than just a concept and can be delivered in practice.

Although we understand that it is not always necessary to define health as 'mental and physical' throughout the entire Constitution, **there must be examples of mental health care pathways** if there are suggestions to include any other right of access. For example, when the Constitution asserts the pledge for a patient to be seen within an 18 week time period, it must also be made explicitly clear, by mentioning 'mental health' that this also applies to all mental health services too.



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## 3.10 Dignity, respect and compassion

National Voices welcomes these proposals.

As we highlighted in our [‘Not the Francis Report’](#), there is growing concern about the capacity of the NHS to deliver basic standards of care to older and other vulnerable groups, with sufficient compassion and protecting people’s dignity. The 2011 inpatients survey showed that nearly 4 in 10 patients who needed help to eat didn’t get it, or only got it sometimes.

To underpin a relationship of respect between professional and patient, letters about a person, should be addressed to that person. We would therefore like to see it enshrined in the NHS Constitution that **all letters from anyone in the NHS be addressed to the patient, and copied to the GP or other consultants as necessary.**

## 3.11 Local authorities’ role

National Voices supports this update and the clarity that it will give to patients in relation to what they can expect in relation to public health services. It will also be important to connect these changes in relation to public health to the point on integrated care above.

## 4. FORTHCOMING CONSULTATION

National Voices welcomes the government’s intention to consult on proposals to give the NHS Constitution more traction in spring 2013.

It is essential that this consultation identifies practical ways in which the NHS Constitution can be given more ‘teeth’. It is not sufficient for NHS bodies to have to ‘take account’ of the Constitution and there should be a requirement on NHS bodies to do everything practicable to uphold the rights and pledges it sets out, and a practical way of them being held to account if they do not. Simply raising awareness of the Constitution, without this underpinning, will only increase patient and service user frustration and damage the credibility of the constitution.

In order to have real impact, the Constitution must also be embedded at every level of the NHS so that staff, providers and patients are fully aware of the principles, values, rights, responsibilities and pledges it contains.

Below are some early suggestions on how to make this happen:

- **Keep it simple and accessible:** although the language of the document is largely clear, there is a lot of content for people to digest. When communicating about the NHS Constitution it will be important to draw on a few accessible and understandable messages and highlight what they mean for people in practice. We welcome the proposal to create summary versions.



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## Case Study: Condition-specific translation of the Charter

Using the NHS Constitution, the Information Strategy and NICE guidelines, the [Epilepsy Society](#) has created a 'your rights and choices' [Charter](#) for people who have (or are suspected of having) a diagnosis of epilepsy.

It sets out rights and responsibilities, along with care pathway through primary, secondary and tertiary care. It seeks to translate the Constitution for the needs of specific patients and make it more accessible. The charter has now also been distilled down into a credit card sized fold out leaflet.

- **A resourced implementation plan:** We welcome the proposal to create a NHSCB communications plan which makes use of multiple existing channels to convey messages that can be retained over time. However, this will have no impact if it is not supported by sufficient resources to be delivered on both a national and local level.
- **NHS Constitution Champion(s):** Who is responsible for the application of the Constitution and the delivery of the implementation plan needs to be clear.
- **Focus on hard to reach or vulnerable groups:** These groups are less likely to come into contact with the key messages through mainstream information channels, but are more likely to need the protections and rights that the document lists. The voluntary sector is well placed to advise on the best ways to reach these groups and to play an active role in raising awareness through their own communication and advocacy activities. The sector is willing to play this role, but the NHS must also be prepared to meet its costs in doing so.
- **Strengthening feedback mechanisms:** The proposals should consider how mechanisms for collecting and responding to feedback can be strengthened, drawing on existing best practice and what concrete initiatives could be put in place to encourage a culture of feedback amongst patients and staff.
- **Advice, support and advocacy:** Some patients may need additional support to understand what the rights and pledges mean for them and what action they can take if they feel that they are not being upheld.
- **Patient Advisory Liaison Services (PALS):** One solution might be to strengthen the Patient Liaison Services (PALS) by putting them on a statutory footing.

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### Contact

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